

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Contents

1. Executive Summary
2. Introduction
3. Method
4. Results from Respondents
 - Workshop Attendance
 - Previous Consultation
 - Discovery of UKPT Workshops
 - Paruresis Duration
 - UKPT Discussion Board Helpfulness in Workshop Attendance Decision
 - Continuing Helpfulness of UKPT Discussion Board
 - Usefulness of Information on UKPT Website
 - Experience of Workshop(s)
 - Paruresis Prior to Workshop(s)
 - Paruresis Post Workshop(s)
 - Restriction Comparison Pre- / Post- Workshops
 - Secondary Processes Pre- and Post- Workshop(s)
 - Taking Part, Occupational and Social Activity Changes
 - Follow up by Telephone and Focus Group
5. Discussion
 - Duration and Severity of Suffering
 - Help and Information Seeking
 - Experience of the Workshop(s)
 - Paruresis and Quality of Life Following Workshop(s)

Executive Summary

The United Kingdom Paruresis Trust (UKPT) is the only body in the UK with a sole remit to help sufferers of the psychological disorder, Paruresis. As a charitable body it is concerned to evaluate the effectiveness of workshops it provides. An online questionnaire survey of the views of participants was designed and implemented. This demonstrated, across a wide range of prior severity levels in participants, highly beneficial changes in the manifestation of paruresis and in participants' quality of life. The survey also indicated very high levels of usefulness of the information provided on paruresis on the UKPT website, and of support provided by the UKPT online discussion board. The survey gave indications of the difficulties that respondents had experienced in finding appropriate information and help before they engaged with UKPT.

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Introduction

This report concerns the development, administration and results of an online survey of participants' assessments of workshops and information provided by UKPT and participants' progress in overcoming paruresis.

Paruresis is a common and widespread life-limiting psychological disorder that is barely acknowledged or discussed in public. Otherwise known as 'Shy Bladder' it is classified as a Social Anxiety Disorder in the Diagnostic and Statistical Manual (DSM V) of the American Psychiatric Association. The primary symptom is persistent difficulty in passing urine in the proximity of other people, associated with varying levels of anxiety. Secondary symptoms include further anxiety problems, social avoidance, depression and, in extreme cases, suicidal ideation and behaviour. Paruresis has commonalities with other social anxiety disorders that disrupt simple body functions such as eating or speaking in front of others, but is very commonplace with an estimated 7% of the adult population estimated to be suffering from it at clinically significant levels (Soifer, 2001); that is over 3 million adults in the UK alone, indicating a vast number suffering in silence, due to a general lack of awareness and acceptance of the condition.

The UKPT has been running weekend residential workshops in London and Manchester for those suffering from paruresis since 2003. In this time 529 participants have attended Beginners' Workshops of which 268 have gone on to attend at least one follow-on Improvers' Workshop. Participants from throughout the UK and Europe have attended, Their conditions ranged from mild, that is with only mild disruption to everyday living, to very severe, where they suffered very severe restriction within their daily lives and the quality thereof. All participants had been suffering from secondary problems, including depression, poor self-esteem and further social anxiety disorders, to varying extents.

Workshops use a proven Cognitive Behavioural Therapy framework within the context of group support and disclosure. This structured approach has been initially developed in the USA by Stephen Soifer, ('Shy Bladder Syndrome' Soifer et al., 2001) and has been adapted according to cultural needs and informed by on-going developments in the field.

Evaluation questionnaires are completed following each workshop. While such immediate feedback is almost invariably highly complimentary towards the content and process of the workshops, and indicative of immediate significant psychological and behavioural change among participants, there was concern that such gains might not be sustained or furthered over time. The present study was conceived with the objective of determining the effectiveness of the programme for participants over the long term.

Method

A 23 item questionnaire was developed (Appendix 1) and set up on an internet online survey site. An email letter of invitation with a link to the questionnaire was sent out to 529 people who had previously participated in either a Beginners' or Improvers' workshop, or both.

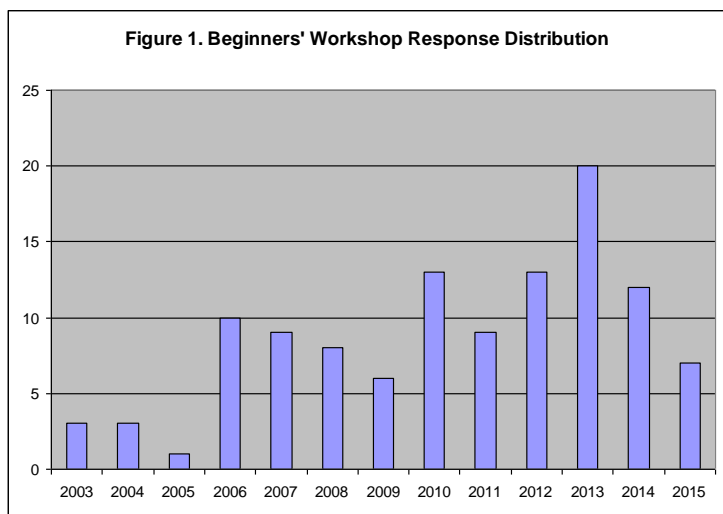
An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Results

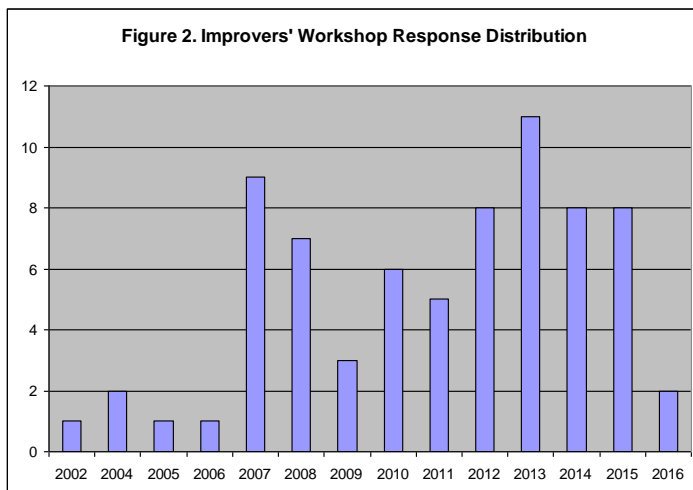
Of the total of 529 invitations to take part in the survey that were sent out to past participants in Beginners' and Improvers' workshops, 114 respondents completed the online questionnaire, representing a 21.5% response rate. This is considered reasonable, considering the 14-year range over which participants had attended workshops. In terms of gender distribution, 92% of respondents were male and 8% female. It is not known how representative this is of workshop attendance gender distribution.

Workshop Attendance

All the 114 respondents identified the year in which they attended a Beginners' Workshop. This distribution is shown in Figure 1.



There was a 2/3 - 1/3 split between respondents attending and not attending Improvers' Workshops, at 64% attending to 36% not-attending.



Of the 114 respondents, 72 identified the year of their participation at an Improvers' Workshop. This distribution is shown in Figure 2.

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Previous Consultation

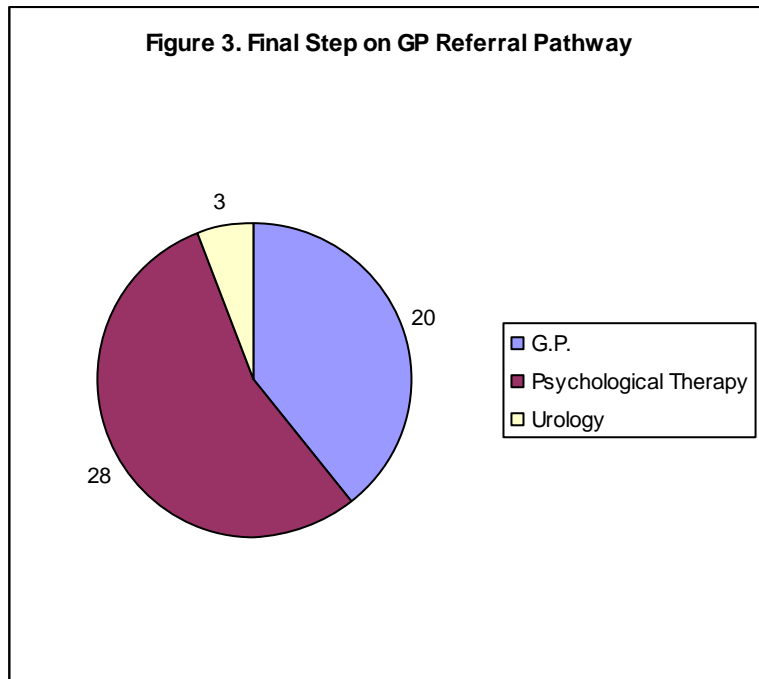
67 of the 114 respondents had consulted a health professional before attending the Beginners' Workshop, while 47 had not seen anyone about their paruresis.

Of the 51 (Figure 3.) who had previously consulted a G.P., 31 were referred on. Of these, 21 were referred to a Psychological Therapist, 3 to a Urologist and 7 to both Psychotherapy and Urology.

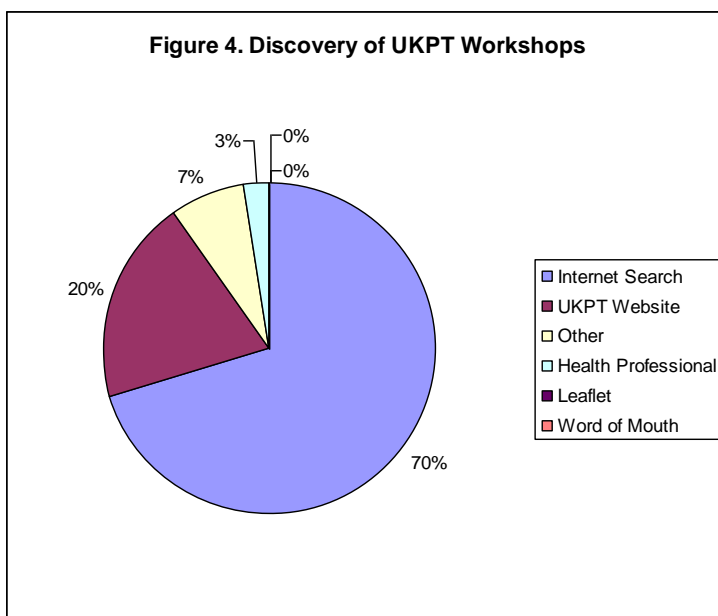
16 respondents who consulted about their paruresis before coming to a workshop did not see their G.P.. Of these, 6

respondents self-referred to a Psychological Therapist and 3 self-referred to a Urologist. Others self-referred to Hypnotherapist (7), Psychiatrist (1), Acupuncturist (1), Naturopathist (1).

Thus 41% (47) of all respondents had not sought any professional help for their paruresis and of the 45% (51) of respondents who consulted with their G.P. only 60% (31) were referred on for specialist help.



Discovery of UKPT Workshops

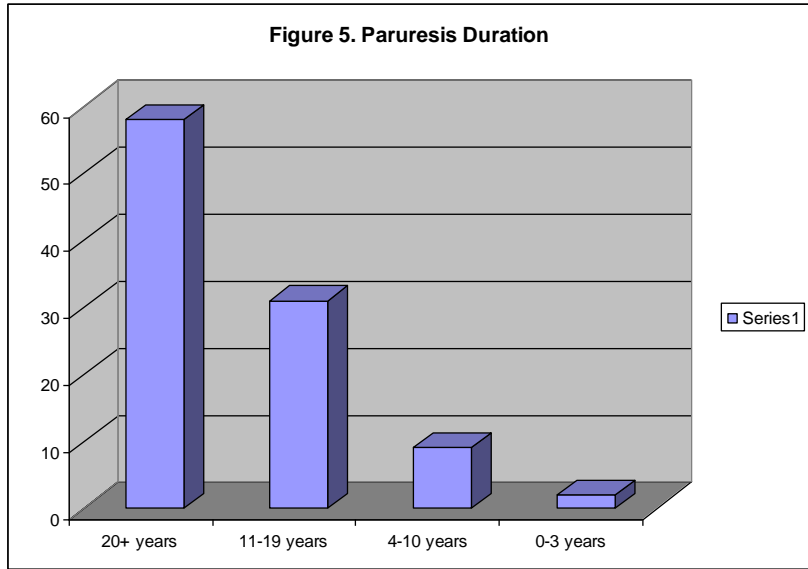


The vast majority of workshop participants (90%) discovered workshops through the internet, either by accessing information through the UKPT website, or through use of a search engine. Health Professional recommendation played the smallest positive role, while Leaflets and Word of Mouth had no effect. This is shown in Figure 4.

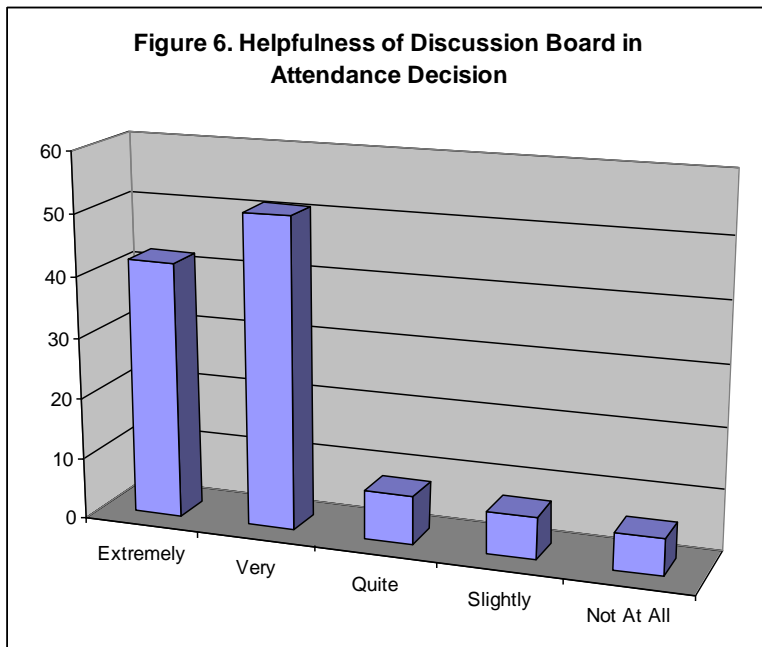
An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Paruresis Duration

The distribution of paruresis duration length was significantly skewed, with 89% of all respondents experiencing paruresis for more than 10 years and 58% of all respondents for more than 20 years. See Figure 5.



UKPT Discussion Board Helpfulness in Workshop Attendance Decision

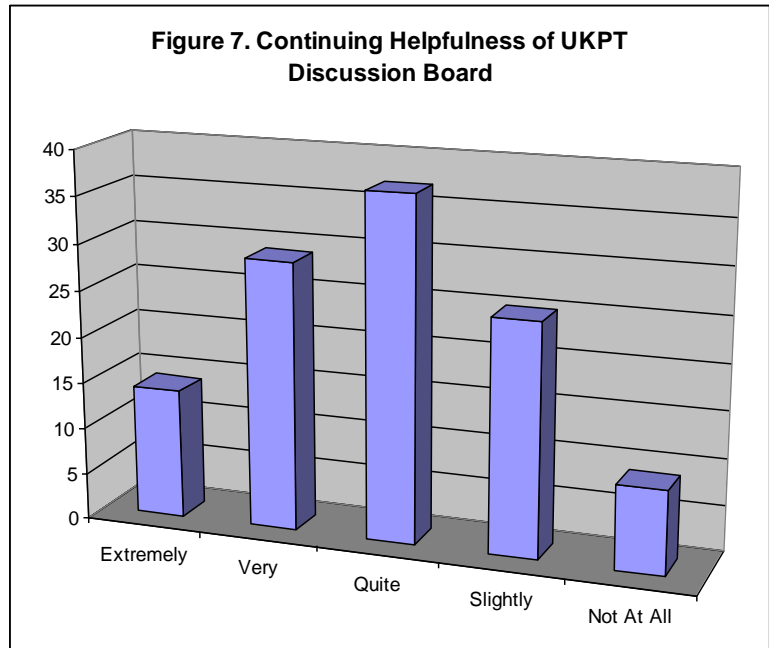


82% of respondents found the Discussion Board comments from previous workshop participants either 'Very Helpful' or 'Extremely Helpful' in making their decision to attend a workshop. Only 5% found Discussion Board comments 'Not At All Helpful', while 13% found them either 'Quite Helpful' or 'Slightly Helpful'. The mean rating of helpfulness was 4.02/5.00 ('Very Helpful').

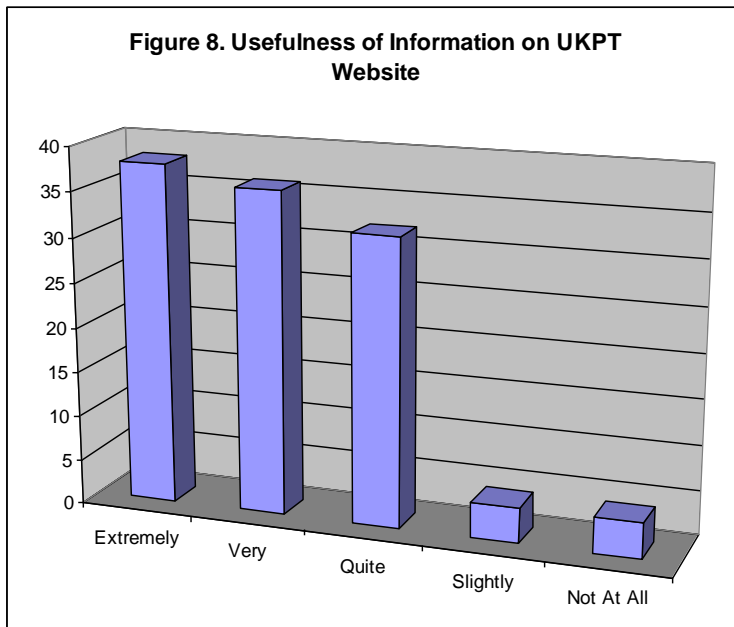
An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Continuing Helpfulness of UKPT Discussion Board

Respondents were asked to rate the degree to which they found the Discussion Board helpful following their attendance at workshop(s). 37% of respondents found the Discussion Board to be 'Very Helpful' or 'Extremely Helpful' subsequent to workshop attendance, 54% found it either 'Quite Helpful' or 'Slightly Helpful', while 8% found it 'Not At All Helpful'. the mean rating of helpfulness was 3.12/5.00 ('Quite Helpful').



Usefulness of Information on UKPT Website



93% of respondents found the UKPT website to be either 'Very Helpful', 'Extremely Helpful' or 'Quite Helpful'. Only 7% found it to be 'Slightly Helpful' or 'Not At All Helpful'. The mean rating of helpfulness was 3.88/5.00 ('Very Helpful').

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Experience of Workshop(s)

Questions in this section concerned three factors:

1. Did the workshop(s) provide increased knowledge about paruresis?

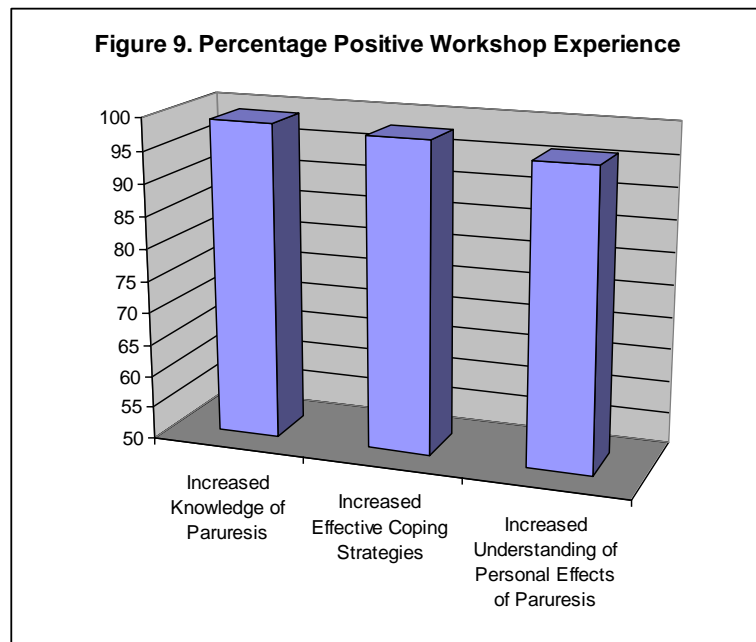
99% of respondents experienced an increase in their knowledge of paruresis.

2. Did the workshop(s) provide an increased understanding of how to develop effective coping strategies?

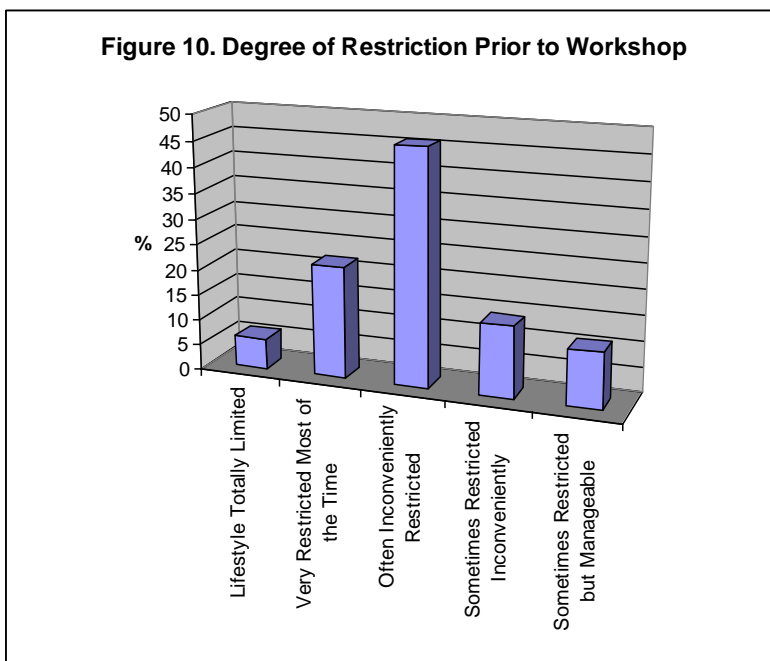
98% experienced an increased understanding of effective coping strategy development.

3. Did the workshop(s) provide an increased knowledge of how paruresis affected the individual respondent?

96% experienced an increased understanding of the personal effects of paruresis.



Paruresis Prior to Workshop(s)

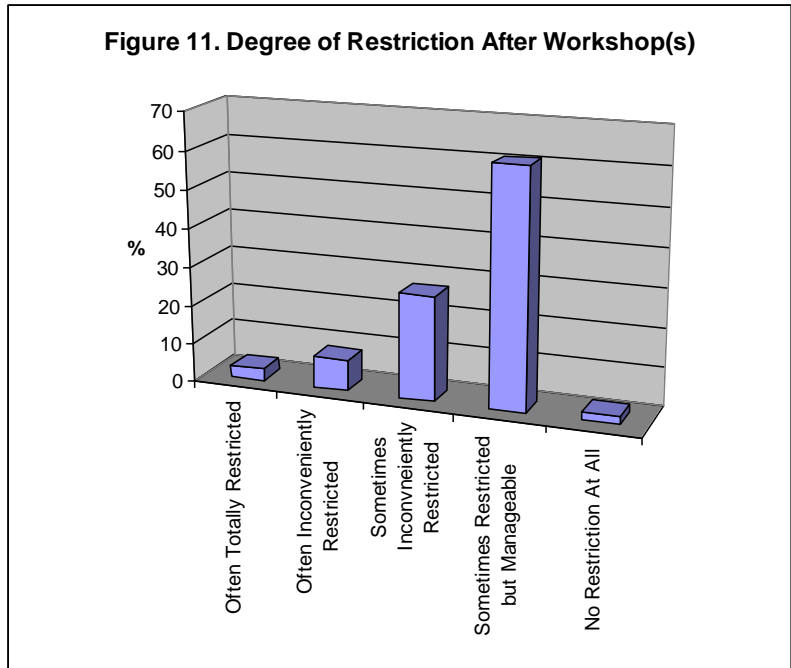


Degree Restricted by Paruresis Prior to w/s	n	%
Lifestyle Totally Limited	7	6
Very Restricted Most of the Time	25	22
Often Inconveniently Restricted	53	46
Sometimes Restricted Inconveniently	16	14
Sometimes Restricted but Manageable	13	11

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

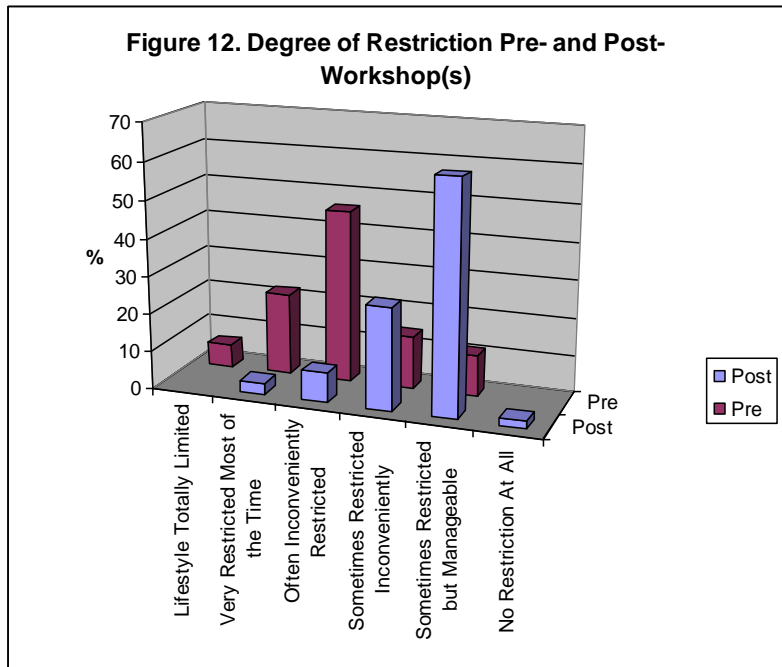
Paruresis Post Workshop(s)

Degree Restricted by Paruresis Post w/s	n	%
Often Totally Restricted	3	3
Often Inconveniently Restricted	9	8
Sometimes Inconveniently Restricted	31	27
Sometimes Restricted but Manageable	69	61
No Restriction At All	2	2



Restriction Comparison Pre- / Post- Workshops

Degree Restricted Pre- and Post w/s	% Pre	% Post
Lifestyle Totally Limited	6	0
Very Restricted Most of the Time	22	3
Often Inconveniently Restricted	46	8
Sometimes Restricted Inconveniently	14	27
Sometimes Restricted but Manageable	11	61
No Restriction At All	0	2



An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

While no statistical tests have been used, it is evident at face-value that the workshops have had a very marked beneficial effect in reducing restriction and limitation resulting from paruresis, with the implication of significant reduction in paruresis itself.

Secondary Processes Pre- and Post- Workshop(s)

These questions concerned processes secondary to the paruresis itself, e.g. rumination, anxiety, attitudes to the paruresis and its effects, avoidant planning, etc.

All 114 respondents provided single or multiple 'yes' answers to the questions in this section.

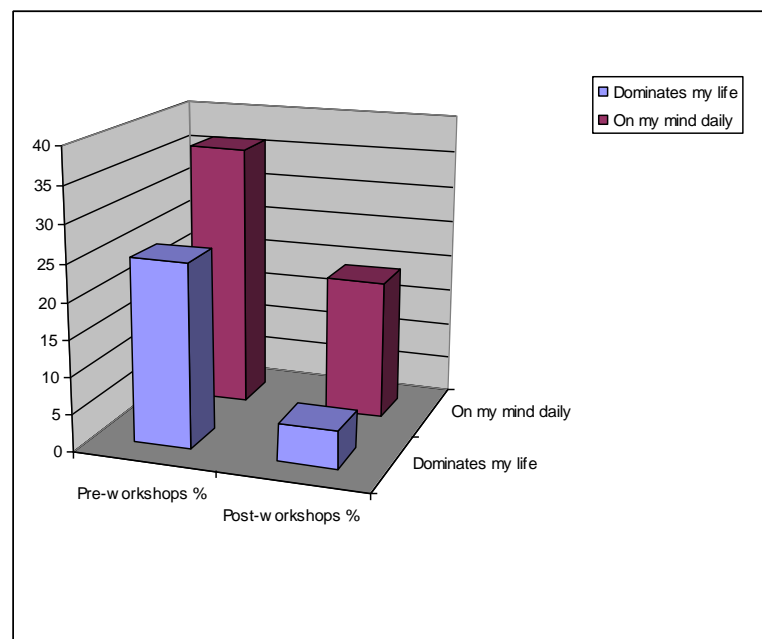
Pre- Workshop(s)

	n	%
1. I planned most of my activities around it and became anxious if required to do something which I could not plan safely	60	53
2. It restricted my life causing me a lot of anxiety	47	41
3. It was on my mind daily and caused me some stress	41	36
4. I felt inconvenienced by it some of the time	36	32
5. It dominated my life and I worried about it constantly	25	22

Post- Workshop(s)

	n	%
1. I am more accepting of it than I was but still worry about it	56	49
2. Most of the time I am relaxed and accepting about my paruresis and whatever limitations I have	50	44
3. It is still on my mind daily	22	19
4. I am totally relaxed and accepting about my paruresis and whatever limitations I have	12	11
5. It still dominates my life	5	4

The only directly comparable questions from Pre- and Post-questions are questions 3 and 5. The number of respondents who said that their paruresis was on their mind daily has halved, while the number of respondents for whom their paruresis dominated their lives has reduced to one fifth of its earlier level.



An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

Taking Part, Occupational and Social Activity Changes

Respondents were asked if they had been able to take part in life since the workshop(s) in ways that had not been possible before.

	n	%	
Take part in group activities	48	42	Over 40% were able to take part in social activities that had not been possible before workshop participation and a third of respondents were now able to go out to clubs and pubs that had previously not been possible. A quarter of respondents were now able to go on holiday.
Go pubbing / clubbing	41	36	
Go on holiday	27	24	
Change job	11	10	
Get a job	4	4	
Go for promotion	4	4	
Other	33	29	

Follow up by Telephone and Focus Group

Half of the 114 respondents were happy to be contacted by telephone for further information about their views and experiences while half were also happy to attend any focus groups that might be arranged. Names and contact details were supplied accordingly.

Discussion

This survey considered a range of factors underpinning and resulting from the participation of those suffering from avoidant paruresis in the weekend Beginners' and Improvers' workshops run by UKPT, which aim to ameliorate this social anxiety disorder through three main approaches: information provision, sharing and support, graduated in-vivo desensitisation.

The survey questioned respondents in four areas: levels and duration of previous suffering; help and information seeking and how they found out about the UKPT workshops; their experience of the workshop(s); their levels of suffering and quality of life since attending the workshop(s).

Statistical analysis was not carried out. With such, it might have been possible to determine if there were any relationships between such factors as duration of paruresis, severity of paruresis, professional help seeking, experience of workshop, recovery level, quality of life.

However, even without statistics and just looking at percentages, some striking results emerged, demonstrating the great effectiveness of the workshops run by UKPT.

Duration and Severity of Suffering

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

The facts that nearly two thirds of respondents had been suffering from paruresis for more than 20 years and 9 out of 10 respondents for more than 10 years before attending a Beginners' workshop is both surprising and alarming, especially given the demonstrated effectiveness of this peer-supported self-treatment approach. These facts are likely influenced by the stigma and shame as much as by the lack of information and treatment resources associated with paruresis. It is the aim of UKPT over time to change the nature of this distribution so that paruresis sufferers are helped much earlier, through greater availability of information, acceptance and treatment for the disorder.

The severity levels of paruresis for respondents before workshop attendance appear to match with evaluation questionnaires completed at the time. That is about 1 in 20 very severe, a quarter moderate to severe, half moderate and a quarter at mild level.

Help and Information Seeking

Perhaps surprisingly, over 40% of all respondents had not sought any professional help for their paruresis before attending a workshop. 45% of all respondents sought help from their GP, of which 3/5 were referred on to specialist services, including psychological therapy and urology. This begs the question as to what sort of treatment, if any, was provided to the 20 respondents who were not referred on by their GP.

The UKPT website Discussion Board was either 'Extremely Helpful' or 'Very Helpful' to 82% of all respondents in making their decision to participate in a Beginners' Workshop, while only 5% found Discussion Board comments to be 'Not At All Helpful'. Thus is demonstrated the great importance of the Discussion Board in supporting the decisions of would-be participants. Following attendance at workshop(s), the Discussion Board did not provide such a 'Very Helpful' resource to respondents, ratings showing a median of 'Quite Helpful' (54%).

The Usefulness of Information on the UKPT website was rated between 'Quite Useful' and 'Extremely Useful' with the median of 'Very Useful'. Only 4% found the Information 'Not At All Useful'.

These results demonstrate the paramountcy of the UKPT website and discussion board in providing useful and helpful information about paruresis and the experiences of those who have attended workshops in aiding and supporting decision by potential and actual participants, not least because for the 41% of all respondents who did not seek professional help, the UKPT website was the main pathway to their getting help.

Experience of the Workshop(s)

The workshop(s) themselves had a dramatic effect upon respondents' levels of knowledge about paruresis, their understanding of coping strategies and that of the specific effects of paruresis for themselves. In each of these areas over 95% of all respondents indicated increased levels of knowledge and understanding resulting from workshop attendance.

In terms of the effects of workshop attendance upon the manifest problem of paruresis there are dramatic findings. In particular, there is a clear and large improvement rate reported in the comparison between levels of restriction resulting from paruresis before the workshop(s) and levels of restriction after the workshop(s), with an approximately 6-fold reduction in restriction

An Evaluation of Psychological Desensitisation Workshops Provided by the United Kingdom Paruresis Trust

(Figure 12.). Following the workshop(s) the number of respondents who reported their lives totally restricted dropped by at least a factor of 2 from 6 to less than 3, while 2 reported that they were free of any restriction at all.

Paruresis and Quality of Life Following Workshop(s)

Questions in this area showed that most respondents are more accepting, and some completely accepting, of their paruresis since attending workshops. There was a massive reduction in the degree to which participants experienced their paruresis as dominating their lives from 22% to just 5%. The degree to which respondents' paruresis was a daily worry reduced by half following the workshop(s).

These findings corroborate the results shown by the post-workshop questionnaires that are routinely distributed and completed by participants and demonstrate that such gains can be maintained long-term.

In terms of quality of life, notable increases (up to 40%) in a range of social activities were reported by respondents following their workshop attendance and (presumably) continued self-regulated desensitisation practice.

Peter Daw MSc Clin. Psychol.
Hon. Adv. UKPT

December 2016